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ABSTRACT

The popularity of home care for chronically ill or technology-dependent children has moved professionals into unfamiliar settings. Factors responsible for the relatively sudden surge of effort to place children with complex needs at home include costs, individualism and autonomy, changing views of medicine and its institutions, limits of medical technology, and growth of technical capability. The movement carries many imperatives for behavior and attitude changes in adapting to the public nature of the care, the need for families to assume risks usually assumed by hospital staff, and the need for professionals to dissociate the management of risk from their direct control. Bringing home the medically complex child may create problems which must be anticipated by candidate families, such as loss of privacy, terror concerning the patient's survival, role confusion, exhaustion, endlessness, and guilt. Participation of caretakers from outside the immediate household requires establishment of criteria for training and clear negotiation of the terms of the arrangement. Psychological concerns of professionals who participate in home-care planning include belief in the hospital as the best locus of care and the nature of professional responsibility. The plan for discharge should consider the: adequacy of funds, screening and supervising of paid and volunteer caregivers, best use of home space, respite care, and other issues. Includes 11 references. (JDD)

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PSYCHOLOGICAL ISSUES IN PEDIATRIC HOME CARE

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PSYCHOLOGICAL ISSUES IN PEDIATRIC HOME CARE

Pediatric home care is an exceptionally diverse endeavor, covering a wide range of initiatives, from the care of children dependent on extremely complex technology to the endless management of the mentally retarded or neurologically impaired child who needs assistance in the basic activities of daily life, such as feeding, ambulation, and personal hygiene, or the learning-impaired child who requires of the caretaker constant vigilance about educational opportunities, legal entitlements and the quality of the instruction the child receives. It is presumptuous to assume that a survey can be made of the psychological consequences or hazards that accompany each of these situations, or to imagine that the wide variety of possible parental or professional responses can be categorized. However, it is possible to reflect on experience, and to draw from those reflections some generalizations about the attitudes, reactions, comforts and discomforts, and anxieties which the involved professionals and the child's caretakers manifest, with the hope of understanding and predicting the likely behaviors of the many actors involved in pediatric home care. Even more important, it is my hope that these reflections may help those who plan and implement the growing number of pediatric home care ventures in the future; understanding the psychological state of the child, of the family and of the responsible professionals may help to avoid unnecessary conflicts or failures. It is particularly important to understand the motives and concerns of the professionals who are making the initial decisions for the child's

discharge and continuing oversight once home; their attitudes and behaviors will ultimately set the tone for all who participate and thus importantly affect the outcomes.

My and my colleagues' experiences from which these observations are derived are in the world of pediatrics; we have been participating in and watching the evolution of pediatric home care for technology-dependent children for nearly a decade. It is my belief, however, that many of the generalizations and cautions deriving from our experiences have equal validity in the consideration of home care for the adult with complex medical needs. The fundamental dilemma of solving one set of problems (for the patient) at the cost of creating a new set of problems (for both the patient and the caretakers) exists no matter what the age of the patient or the constellation of the family into whose care that patient is transferred. The profound burden placed on the primary caretaker(s) is nowhere more dramatic than in the situation where an elderly infirm person is sent home to the care of an elderly mate, whose own health may be marginal. Thus, pursuit of one dependent person's interests may result in the crippling of another because of the demands of care of the first. The analogy between this circumstance and that of the family of the technology-dependent child is apparent, and it is not surprising that similar types of reactions and risks occur.

The relatively recent popularity of home care for chronically ill or technology-dependent children has moved professionals into unfamiliar settings with great rapidity, often without time for contemplation of the significant changes in attitudes and priorities which home care demands. Yet, understanding of the personal and social forces which pediatric home care is part of and which it contributes to is essential; there must be

congruence between these social realities and the knowledge and expectations of the professionals and families alike to achieve a successful home care program. Coerced or uninformed choices will always predict for failure, or at the very least, continuous conflict and psychological discomfort for all or some of the parties--parents, patients, caretakers and professionals--involved in a given home care plan.

For those children who are discharged to home dependent upon complex technologies, such as ventilators or dialysis, there is an additional important, yet unclear, element in both societal and personal constructions; we don't yet appear to have developed a clear and concensual view of the combination of child and machine. This chimeric creature, sometimes seen and spoken of as a child connected to a machine, sometimes as a machine supporting a child, is perplexing. While all--parents and professionals alike--would profess that the child is the center of our concern, the imperatives of management of the equipment and technology often dominate conversation and awareness. We become obsessed with the complexities of the technology because of our concerns for safety, our fascination with the gadgetry and its possibilities and our reaction to the tyranny it imposes; the machine becomes a looming presence and threatens to obscure our vision of the child. We begin, then, to think of the human and the inanimate as inseparable, and there is often a necessity to deliberately remind ourselves and others that the child's welfare--both short and long term--was and should be the main concern. Neither society as a whole nor its individual members has yet elaborated a value system, much less a consistent description, for these relatively new child-machine pairs. How much is a five thousand dollar ventilator worth

when a child's life depends upon it? And, can we *really* plan for and unconditionally love a child who is totally dependent on technology for survival? Given these real uncertainties and confusions, and the challenges to conventional attitudes and assumptions inherent in home care for children traditionally hospitalized for the same illnesses and disabilities, it should not be surprising that inconsistencies and conflicts occur in the processes of planning for, implementing and maintaining a complicated home-discharge plan.

PEDIATRIC HOME CARE: A RECENT HISTORY AND SOME INTERPRETATIONS

It must first be acknowledged that pediatric home care for children with special needs is not a new phenomenon. Parents and others have been taking care of children with congenital anomalies, mental retardation and crippling disorders for generations, with quiet determination, often with success against huge odds, and usually without the professional and societal support or attention which characterizes the recent movement for home care for technology-dependent children. What factors are responsible for the relatively sudden surge of effort to place children with complex needs at home? And, is this truly a major shift in attitudes or more simply an uncoordinated response to a set of pressures coming from several directions simultaneously and converging on an especially vulnerable population of children and their families?

COSTS: Certainly, contemporary concerns about the costs of medical care have been important in bringing the population of technology-dependent children into public attention; these children tend to be high-cost, long-term patients, whose financial requirements are often used as

exemplars of the dilemmas of resource allocation which society faces. More important, these children stimulate not only discussions of the benefits to be achieved from continued investment of cash resources, but also of the restrictions of continued residence in institutions dedicated to the application of high technology. Serious questions can and must be raised about the negative consequences of such prolonged residence, even with the assurances of the child's safety and access to emergency services which such institutions provide. Is there a long-range calculus of diminishing returns which makes home-care ultimately the preferable alternative? Clearly, if this choice is made, then the foregone benefits, real and psychological of the hospital, must be rationalized by the parents, the professionals and, where appropriate and necessary, by the child.

INDIVIDUALISM AND AUTONOMY: Concerns about patient and family autonomy have become prominent in contemporary discussions in pediatric ethics; certainly, there has been a serious effort to reassess traditional attitudes and practices which grow out of professional paternalism, and to give to patients greater voice in the selection of their therapies, more information about side effects and the relative risks of therapeutic choices and the right to reject therapies, even those felt to be important by the medical professionals involved in the case. At the same time, with increasing affluence and in a political climate which seems to glorify the "rugged individualism" so characteristic of the American ideal, there is growing assertion of that individualism, whether in the pursuit of freedom of choice, in the reaction against bureaucracy, or in the departure from conventional wisdom. Traditional professional and institutional routines and dicta are increasingly seen as unnecessarily rigid and

bureaucratic, and ultimately, as paternalistic. Such a climate leads to a search for new ways to do things and for new sources of authority, greater self-sufficiency, and a willingness to "take things into one's own hands".

CHANGING VIEWS OF MEDICINE AND ITS INSTITUTIONS: The public's views and expectations of American medicine have undergone great evolution in recent decades. There is increasing questioning by the public of the altruistic motives of physicians and administrators as cost containment, open competition in the medical market place and malpractice litigation lead to reorganization for what appear to many to be profit-seeking motives, the practice of defensive medicine, the enlarging of the group of under-and unserved poor, and the growing impression that hospitals are unwilling to care for patients who cannot pay the rapidly escalating costs of care. These issues especially have meaning for the families of children with long-term special health care needs; they require disproportionate amounts of hospitalization and other costly medical services, are generally less well-insured than the population of children in general, and are thus among the least attractive financial risks. At the same time, there is a creeping mistrust of large complex institutions and a tendency to decentralization and individualization of human service programs, as the United States with its many different cultural, geographical and social subdivisions comes to grips with the failures of large centrally-controlled public schemes. The hospital, both in concept and in practice, represents one of the most prominent of those 'large' institutions; while those in the professions and in hospitals view their practices and their individual institutions as unique, they are are often seen as indistinguishable and monolithic by the

public.

THE LIMITS OF MEDICINE: There is growing recognition, both by the public and by the professions, of the limits of possibility and capability of medical technology. Indeed, we have all become increasingly aware of the consequences of excessive dependence on new technologies to solve the fundamental questions of human mortality as those new technologies spawn new ethical dilemmas about their proper use. It is also now almost a truism that the more complex the technology and the setting in which it is used, the greater is the possibility for error; the demands for human sophistication in the use of new technologies threaten to bypass the capabilities of the present cohort of professionals. Thus, the spectre of serious error grows in the public imagination, and, indeed, in fact. The perceived possibilities and real occurrences of error in traditional professionally-controlled environments add to the demystification of professionals and their pronouncements; more and more, well-informed patients feel empowered to make decisions and choices and to exercise them, even if they are variant from those of the professionals.

Among the increasingly frequent complaints about hospitals are concerns about the loss of individual dignity in hospital settings and the inability of the individual patient and family to assert their identity and choices in the rigid and ritualized hospital environment. Thus, the possibility of transferring the locus of care out of the hospital to home may become increasingly attractive as the child's needs stretch out into the long term.

One of the important limits of contemporary hospitals, agreed to by both parents and those caring for their children, is the inappropriateness of the hospital as a site for long-term residence for a child who, while

still requiring care and technology, is now stabilized--that is, not subject to rapid or serious fluctuations in medical status. For that child, while there may be have to be periodic changes in medical care, the major concerns are for the developmental and affective needs of the child. Acute-care hospitals are not equipped nor staffed to address those needs well; the child is thus at risk of having these very important issues neglected or managed poorly, and important developmental opportunities may be delayed or missed completely.

THE GROWTH OF TECHNICAL CAPABILITY: It is deliberate that the growth of technologic capability is discussed last among the environmental and social factors which have fostered the movement toward pediatric home care. While the growth of portable technology for support and monitoring of children with complicated disorders has made their care at home possible, it is my view that without the accompanying social factors just discussed, the possibilities would lie unfulfilled. Indeed, as the home care initiative grows, new problems and second thoughts are emerging, not necessarily because of technological failures, but because of the the recognition that the American social and family structures have changed even while the acceptance of home care has grown.

The result is a new set of dilemmas, as we appreciate the intense stresses of having a dependent child (or for that matter, an adult) at home, at the same time that the majority of mothers are now in the work force. It is becoming apparent that, in pursuit of the best interests of the adult or child with special health care needs, simply creating the equivalent of an Intensive Care Unit in the home and staffing it is not the

end of the problem; rather, it is the beginning of a whole new set of problems for the parents and the siblings of the patients.

Compounding these problems are the present fiscal disorders of the American health care system which make it advantageous for payors and hospitals to send complicated patients home, but with no certain sources of payment for their continued care. It seems likely that, unless these problems are addressed and solved, even with ever more breathtaking technology, the movement toward home care will quickly stall. These observations lead to the conclusion that the availability of technology for home care is an enabling, but not a driving force; its existence cannot and should not be seen as a mandate for its application.

IMPLICATIONS OF COMPLEX MEDICAL CARE IN THE HOME

The movement of complex medical care from the hospital to home carries with it many imperatives for changes of behavior and attitudes on the parts of all concerned--patients, caretakers (both familial and contracted) and the professionals who assume oversight responsibility. Among these are: adapting to the public nature of the care and interactions; the need for families to understand and assume risks which are usually assumed by hospital staff and rarely discussed with patients or their families; the need for professionals to dissociate the management of risk from their direct and immediate control; and, as a consequence of all of these, the requirement for much greater disclosure of risks, level of competence and the uncertainties of prognosis and possibility which are often not disclosed (by the professionals) or not probed (by patients and families) when a child is in the hospital. Each of these will be discussed

in turn, but first it is necessary to describe some of the salient realities of the medical care of technology-dependent children in the home.

It is not surprising that, at least initially, the child discharged to home becomes the focus of all the family's activities, energy and planning. The excitement and pleasure of bringing home a child who has spent months or even years in the hospital is unmatched. However, while a properly-done discharge process will have prepared the family for the transition, the reality of having the child at home, with the armamentarium of the hospital suddenly distanced is inevitably sobering and often frightening. A combination of these feelings and the need to be vigilant and attentive to the child, while carrying on ordinary activities of the household can lead to exhaustion, which, in turn, may make the negative and frightening aspects of the venture loom larger.

If the child requires the steady or frequent use of complicated equipment, the parents will have to have acquired rather extensive knowledge of that equipment in order to do at least minimal trouble-shooting. In some instances, the knowledge will have to be more extensive, either because of the complexity of the device, and/or the length of time required for skilled service or consultation to be obtained. One thing is certain: the parents and caretakers will have been heavily indoctrinated to understand the consequences to the child of either mechanical or human failure. Thus, they must, almost by definition have high anxiety levels. No amount of rehearsal before discharge (and much is needed) will completely allay the anxieties and stresses of bringing a child home whose fate has now been placed clearly in the hands of parents and the other caretakers they oversee.

Some families may not be able to comprehend and synthesize all that is required; for fear of appearing incompetent or poorly motivated, they may conceal their incapacities until the child is actually in the home. More likely, they may overestimate their psychological capabilities or underestimate the real challenges that having the child home brings. Even the most attentive and thorough discharge planning team is unable to accurately judge the real intellectual or psychological capacity of a family until the child is actually home. The longer and more meticulous the discharge.process, the greater the likelihood of doing so, but the first days and weeks at home are the only true test.

On the opposite side, it is not uncommon for professionals to underestimate the capabilities of the family members; such a miscalculation can seriously impair the flow of the discharge process, if parents' confidence in themselves is undermined by unduly skeptical attitudes of the professionals helping in their preparation for home discharge. The parents' ability to identify real crises and to respond appropriately can only be tested by approximation during the discharge planning process. The early days and weeks of the child's stay at home strain all the physical and psychological capabilities of the entire family; even if no serious complications or medical management problems occur, each of the elaborate systems set up in the discharge process--hired caretakers, medical supplies, equipment repair and maintenance, financial supports--will have to be tested, verified and incorporated into the family's routines.

THE PSYCHOLOGICAL CONSEQUENCES OF CARING FOR A MEDICALLY-COMPLEX CHILD AT HOME

That there are many benefits in caring for a chronically ill or dependent child at home is unquestioned. The reduction of anxiety in familiar surroundings, and the shift in focus to recovery and function from illness and helplessness is essential to allow all possible improvement, both physical and psychological, to occur. Almost all patients, young and old, exhibit a sense of enhanced autonomy and control when home. Great leaps of developmental progress in children and of increased confidence and reduced dependency in older persons often begin shortly after discharge. The familiar routines of family interaction and patterns--of comings and goings, meals, jokes, the private rituals of every family--have curative and enhancing powers in themselves. The reduction in the numbers of strangers and caretakers which characterize the hospital environment helps to reestablish bonds which were severely strained, or, for the infant, never made in the first place.

The same positive effects also potentially exist for the caretakers. However, the anxieties attendant upon receiving a child with complex needs at home may mitigate or even totally override the advantages for the caretakers. The first few days and weeks, especially, are critical times for the success of a home care program; if the caretakers cannot be helped to overcome the natural and inevitable worries of the new and potentially frightening situation, the venture may take a steadily downhill course, resulting in readmission for the child and great guilt and sense of failure for the parents. On the other hand, if they can see beyond that first period, and begin to savor the benefits to the child and themselves, an important threshold will have been passed.

With a reasonably smooth transition from hospital to home, the family and other caretakers can also begin to realize the benefits of the conservation of resources--physical, fiscal and emotional--which travelling to and from the hospital demands. In the simplest terms, this means that there is more to give--more for parents to give each other, more to give to unaffected siblings and other family members, more to give to the affected child--and more available for self-care.

These advantages of bringing to care at home the medically-complex child may, however, be mitigated or erased by a number of problems which must be anticipated by the candidate families and understood by the professionals planning the discharge. Appropriate counter-measures should be built into the preparations for home discharge and long-term care. I will discuss some of these issues, identified from our experience and that of our colleagues. For some, the solution or approach is self-evident; for others, the specific family and home-care situation will have to be carefully evaluated, and the approaches tailored to those individual realities.

LOSS OF PRIVACY: The absence of solitude, so essential for each of us in the development of our sense of self, is a major concern for the medically complex home care patient. Because of the understandable anxiety of the caretakers about the functioning of technical support systems, their inexperience in differentiating normal from abnormal, their uncertainty about what matters and what doesn't and when to become alarmed, the patient may never be left unscrutinized or unstimulated by inquiring voices, caring touches or questions about comfort or state of responsiveness. An additional incursion into privacy, especially important for the older child or adult, is the transfer of care of

intimate functions (e.g. toiletting, personal hygiene) from neutral hospital personnel to familiars in the family. This necessity may breach important separations and boundaries, reorder established rituals of privacy, and become the symbol of dependency and infantilization. The latter is particularly an issue for the young child who should be moving toward independence and increasing self-sufficiency; families may need help to meet the demands of their child's care and, at the same time, promote developmental progress.

The loss of privacy for caretakers is also a serious problem. The child's frequent probing "Are you there?" not only traps the parents but also feeds anxiety or guilt about not being available for events of consequence. Parents and caretakers often feel that they must hide the strains and passions of everyday life from the child and others--professionals and volunteers--in the environment. Sometimes parents express guilt about pursuing their own needs when the child's needs seem so much greater. They fear open demonstrations of affection or disagreement; the parents' affective and sexual relationship may thus be seriously compromised. Older children will surely sense these changes, and may, in turn, become anxious or depressed, blaming themselves for being the cause of the parents' unhappiness. Clearly, these kinds of reactions are very detrimental to the child's development and sense of worth; one of the major advantages of transferring the care of the child to the home may thus be negated, and a new set of dysfunctional perceptions and interactions may arise.

TERROR: If anxiety about the patient's survival and their own competence rises to the level of terror, the caretakers' reserves of psychological space and emotional energy are depleted. Terror of that magnitude cannot be concealed; the child quickly realizes the parents' state and becomes anxious as well. If the child is old and sentient enough to feel and react to the caretakers' terror, the child will then become afraid to ask for important or necessary care or adjustments; a state of dual paralysis ensues. Recognition of such family anxiety should precede discharge, but occasionally parents can conceal or fail to recognize their degree of anxiety, and discharge proceeds. When such anxiety is detected after discharge, immediate action must be taken by the involved professionals; the success of the home care program and even the child's safety may be in great jeopardy.

ROLE CONFUSION: While some family members ordinarily provide care for other members, these roles are usually carefully limited and reciprocal; they usually do not include (except for infants and small children) care of intimate functions. When such role boundaries are compromised in acute illness or temporary disability, it is understood that they will be reestablished when the acute episode is over. That understanding makes illness-imposed dependency tolerable for the sick person. No one enjoys forced dependency on others, particularly when those others are family members. Nonetheless, solace, companionship, familiarity, intimacy--the most important and particularistic elements of family relationships----must be maintained. Indeed, these elements become even more essential to the stability and progress of the compromised child or adult. Home care creates the hazard of serious role

conflict, in that the caretakers, as surrogates for professionals and perpetrators of the necessary interventions, are often required to breach boundaries of intimacy, inflict pain, and confront self-pity and perceptions of futility.

The parents of a child in home care usually control the very technologies which are the sources of anxiety and terror. Thus, caretakers have no buffer for their terrors, and at the same time the patient sees familiar sources of comfort become messengers of anxiety and agents of pain. For the caretakers, this situation creates nearly irresolvable conflicts; they must provide solace for the very anxiety and pain they have caused. For children, their anchor has become confused with their tormentor; they must seek reassurance from the same people who are causing them psychological and, in many cases, physical discomfort. Yet these persons remain their parents, with all the authority and ability to induce guilt and fear normally part of the parent-child relationship. There is significant risk that the relationship between child and caretakers may be reshaped as a provider-client or master-slave relationship; the normal development of the child's independence and autonomy may be lost in an authoritarian blitz. None of these is ultimately acceptable. Of course, the unfolding pattern of relationships in a given family after home discharge of a medically-complex child or adult will be heavily conditioned and even predicted by the prior relationships. There is a particular high-risk situation when an affected child is the first-born; parents have no "track-record" from which to extract confidence in their basic parenting skills, much less in their abilities to care for a child who brings extraordinary demands for care and support.

The problems for parents as "case managers" of their children are manifold; yet, in contemporary American society, there is usually no realistic alternative. The physical, logistic and emotional requirements of fulfilling many roles simultaneously can occupy all available time, energy and psychological space. Fatigue and exhaustion are potential nemeses; they, in turn, magnify all the real problems and challenges. Parents are reminded repeatedly of the lost ideal of normal life and family. Children with chronic disease or disability are living reminders of that loss. How parents and families have faced those losses initially will heavily influence how they deal with the child discharged to home care, and their subsequent reactions and success.

The parent or other family member required to leave the workplace to spend full time in care of a relative loses many things: income, freedom, personal growth. Continued resentment in caretakers may even be manifest in subtle and not-so-subtle forms of anger at the affected person. These must be watched for, identified and addressed promptly and vigorously, or the patient as well as the home-care plan may be at risk. Minor acts of omission or commission, unconscious or intended, may have disastrous consequences.

One of the most important reasons for attempting the home care of a medically complex child is the promise of promoting the best possible psychological, intellectual and social development for the child. To achieve that goal in the face of the formidable inherent challenges requires that parents or caretakers first overcome fear. The best way to overcome fear is through education and familiarity with the intricacies of the child's care. Next, the professionals must help the family, child and other caretakers to delineate the responsibilities of each; when the child

can participate in those discussions, many problems of role confusion can be clarified. Ultimately it may be necessary to arrange for purchased or volunteer services for those therapies or interventions which conflict with or destroy the parents' ability to provide indispensable and irreplaceable solace and sympathy; the costs of such services should be considered as part of the necessary and irreducible plan for safe and successful discharge. Those services that can be purchased, should be, when the alternative is the loss of the reassurance that only parents can bring to a child.

EXHAUSTION: The many new, unfamiliar and sometimes frightening tasks required of caretakers are draining. These tasks require constant attention, energy and organization. Inevitably, a high level of vigilance will be demanded, at least initially. The organization and logistics of management may be confusing to those without managerial skills; the resulting inefficiency added to the real demands of the situation can compound fatigue. If uncertainties about fiscal resources are present (as is often the case) worry about money to pay for services and equipment adds to the burden. Even when insurance and other sources of payment are adequate, a myriad of other nagging and endless details remain, such as filling out forms, making phone calls to insure follow-through, waiting for and writing checks.

The actual physical demands of the child's care may also be significant. Transferring and positioning the child, moving equipment, giving treatments (such as physical and respiratory therapies), feeding and personal care all demand physical effort and often much strength. There is always "one more thing to do". Parents constantly seek to find better ways to make the child comfortable, to stimulate, to engage, to

promote interaction and to seek response. Parents and other caretakers must be helped to understand and accept the status of the child and the limits of possibility for improvement. They should be shown ways to conserve their own energies and to organize the tasks before them. They must also be reassured that fatigue is common and not a sign of impending failure. Most important, perhaps, they should be given permission and even encouragement to seek respite for themselves; specific respite plans should be anticipated at the time of discharge if at all possible.

ENDLESSNESS: Chronic illness and disability is characterized by persistence, slow improvement (if any), and an unrelenting need for continuous therapies and services. These realities, along with the prospect of many years or decades--even a lifetime--of dedication of many or all of the family's resources, can foster a climate of despair and hopelessness. The routines of daily care ultimately become neither fearful nor novel; when the patient is significantly restricted in activity or responsive capacity, the possibilities for creative interactions are limited. Caretakers often feel that they are trapped in a web of unrelenting demands on them with the patient at the center. Siblings may find their world constrained by their parents' singular attention to an impaired child. When medically dependent children are old enough to understand the demands which their illness or disability has imposed upon the family, they may also become depressed as they realize that their problems have caused their loved ones such unhappiness. All members of the family may thus join in the perception that "there is no way out".

Continuing financial worries are among the most destructive of problems. Because so many medically complex children and adults are now discharged to home with extremely complicated and usually inadequate funding arrangements, it is likely that concerns about money will be a constant presence. In addition to requiring that one family member forego earning opportunities, the presence of a chronically disabled person in the home may also severely restrict job mobility for the primary wage-earner. The necessity of modifications to the home, the elaborate safety precautions which need to be arranged in the community and the penalty in insurance benefits often associated with job or career change make such changes difficult if not impossible. Thus, opportunities for improvement, both in earnings and in status, may have to be sacrificed. All of these issues can only add to the sense of oppression and endlessness in family which is disposed towards such feelings. These problems must be addressed head-on by the professionals arranging for and following the home care program. To fail to do so, and to fail to institute appropriate countermeasures and support for all the members of the family is to design a home care discharge for ultimate failure.

GUILT: As in all situations in which a child is born or becomes ill or disabled, parents repeatedly search their past actions and behaviors for some role they might have played in the causation of the child's plight. "What could or should I/we have done to keep this from having happened?" While constant reassurance and support for the parents may mitigate these feelings of guilt, it is a fair assumption that they persist in the family at some level. Daily events in the care of a medically-complex child give plenty of opportunities to rekindle or reinforce those guilts and concerns, even if they are latent and seemingly under control. The

intricacies of each of the many therapies and the vulnerability of the child together guarantee that some errors, some slips in technique will occur. These may even cause the child some pain or discomfort which might have been avoided if everything had gone perfectly. Parents will thus have many opportunities to relive and even augment their initial guilt as they perform the necessary daily care of their child.

Older and alert children can perceive the burdens felt by the family. If discussions about money are frequent and emotional, they may feel responsibility for this concern, too. Often children express worry about their siblings, especially if the relationship is or has been close. Dependent children and adults may deduce that their own disappearance would solve many problems for those they loved ones, and suicidal thoughts may ensue. While the most dramatic expression of these could be the manipulation by the child of some critical life-supporting technology, it is more likely that such ideation will be expressed in subtle and less apparent ways, such as deliberate acts of noncooperation or otherwise inexplicable failure of the child to show developmental progress where such improvement is possible and desirable.

PROBLEMS OF THOSE WHO ARE NOT PATIENTS OR FAMILY

The home care of children with special needs, particularly those with complex problems or who use or depend on sophisticated technology will often require the participation of caretakers from outside the immediate household. These may be members of the extended family, other volunteers, or paid professionals who are necessary members of the team of caretakers. Parents must often depend upon the help of

volunteers to assure that the child gets the continuous care and therapies which are part of the home care plan and to capture some respite for themselves from the otherwise endless needs of the child. Such volunteers, whether from the family or from without, have a wide range of motives, from the altruistic to the purely voyeuristic, for wanting to give of their time and energy. Because it is difficult for the family to refuse help from well-meaning people, or to question their motives or skills, it is important that the professionals help them to establish criteria for the training, competence and reliability of the volunteers. Of particular importance is the establishment of boundaries of privacy. These are hard enough to maintain with hired professionals; they may be extremely difficult to establish and enforce when the helpers are familiars, relatives or friends, who may feel that they have license to "know everything" about the patient. All parties--child, parents and siblings and volunteers--must be encouraged to openly set the acceptable limits of knowledge and inquiry about the private affairs of the patient and other members of the family.

With paid professional caregivers, in addition to the previously discussed problems, two additional possible areas of difficulty can arise. The first of these involves the caregiver's privacy. Many home care nurses, aides and technicians report that families have been unnecessarily intrusive about their lives, especially about their children and how they care for them. Sometimes this is harmless curiosity and sociability, but in other situations such intrusiveness may be the sign of envy about the paid caregivers 'normal' children, or may be conscious or unconscious attempts to enhance affiliation with the caregiver in order to press for special dispensations in price or availability of services.

A second area of potential conflict between paid caregivers and family may be excessive demands from the family for time beyond that contracted for or for advice or practice clearly outside of the professional expertise and competence of the specific professional. The relationship between home-care professional and the child and family is necessarily a close and particular one, stripped of many of the formal structures of the hospital which create and sustain clear separation of roles. Thus, it is easy for all parties to forget that the relationships which develop around the child at home are first and foremost instrumental and professional ones; the particular skills which professionals bring to the child at home should not be compromised because of failure to clearly negotiate the terms of the engagement and its boundaries. Anticipation and thorough discussion between families and paid caregivers and volunteers will help to avoid many of the problems discussed; periodic inquiry about and reassessment of these relationships by the responsible professionals are also required to prevent deterioration of effective arrangements.

PSYCHOLOGICAL ISSUES OF PROFESSIONALS WHO PARTICIPATE IN HOME-CARE PLANNING

The chances for success of a home-care plan for a medically-complex child are, to a great degree, determined by the attitudes and behaviors of the professionals who care for the child and come to know the family while the child is hospitalized. The behaviors of the professionals, in turn, reflect the beliefs, values and intellectual habits with which they are most comfortable, or, at least, have rationalized. For this reason, not only must the technical details and processes of home-discharge be well thought through before introducing and executing the discharge process, but the motivations, uncertainties, and any conflicts within and between the members of the professional care team must also be exposed, understood and resolved.

The very language of proposing discharge to home as an alternative to continued hospitalization, or the professionals' reactions to the first inquiry by parents, necessarily condition the likelihood of success of the entire subsequent enterprise. The verbal and nonverbal expressions of the doctors, nurses and therapists is given enormous importance by parents who are uncertain at best; thus, in order to avoid confusing, mixed or conflicting messages, the professionals must have a firm grip on their own values, attitudes, feelings and goals for the patient before discussions about discharge to home are initiated.

It is also important that these discussions, clarifications and disclosures take place among the professional team members in order to preserve their integrity and clear judgment in a situation which defies traditional constructs and the dominant concepts of necessary

professional control. In the same way that it is unlikely that families and patients will be able to proceed to the required levels of competence and confidence in an environment of mixed messages, it is also unlikely that professionals can maintain consistency and commitment over the long run if they are operating in an environment in which they are continually in a state of psychological discomfort.

SOME REFLECTIONS ABOUT HOSPITALS: The belief in the hospital as the best and only locus of care for the very sick and those dependent on technology runs long and deep. The acute-care hospital is the place in which nearly all the medical professions are trained; with recent pressures for cost-containment, the acute-care hospital, even more than in the past, seems to exist only for those patients. Thus, there is an inevitable connection in the minds and expectations of the professionals between patients with complex needs and the hospital setting. While we have idealized what can be and is done in the hospital (and the safety of the hospital, as well) it remains the symbol of the best that we can give to complicated patients. The comforting presence of all the technology that could possibly be needed, no matter what the emergency, and of all the specialists to use that technology on an around-the-clock basis becomes in our minds not only the ideal but also the minimum that should be available. While we accept the inevitability of error and of the unexpected in hospitals, we are comforted by knowing that we have done "all that can be done" in modern technological terms.

Hospitals have also become, in both the public's and the professional's eyes, almost church-like, representing the ultimate recourse and sanctuary; to "desert" them for home care of technology-dependent patients may be seen as a form of heresy, a rejection of

progress, and thus a "second-rate" choice for the patient. This attitude may lead some professionals to reject the possibility of home-care for all but the most desperate and irretrievable, a perspective which will inevitably compromise the effectiveness of the discharge process.

While hospitals do offer capabilities and protection that cannot be replicated in the home, they are also limited in many services which the chronically ill and technology-dependent patient needs after the primary condition is stabilized and the therapeutic programs have been established. Most personal interactions in contemporary acute-care hospitals are with and among strangers. The profusion of professionals and technicians, the constant changes of medical and nursing personnel, the distractions and drama of the crises of fellow-patients all serve to compromise the sense of intimacy, continuity and confidence which the chronically-ill child needs to hasten recovery and growth. The stabilized technology-dependent child, for example, one totally or partially ventilator-dependent, needs "low-technology" services and care--education, the reassurances of family and familiars, sympathy and encouragement--all essential for adaptation to living and growing with a disability. These are not the things that acute-care hospitals do best--nor, should they necessarily. It is neither cost-effective nor efficient to equip hospitals as surrogate homes; an attempt to do so would dilute the resources required for their primary missions. Finally, it is recognized by all concerned that patients with very complex needs, requiring the coordination of a multiplicity of interventions and personnel, are increasingly at risk of serious error as the length of their hospitalization grows; in fact, the few studies reported which look at undesirable outcomes in the hospital versus those which occur in home care for

chronically ill children show comparable morbidity and mortality in the two settings.

Nonetheless, even with acknowledgement of the deficiencies of acute-care hospitals for the stabilized child with complex needs, it is likely that some traditional hospital-based professionals will have discomfort with or resistance to the idea of sending such children home. This reality must be acknowledged, addressed and thoroughly discussed among the members of the discharge team before the plan for discharge is initiated, or else the successful execution of that plan will be seriously endangered.

THE NATURE OF PROFESSIONAL RESPONSIBILITY: Physicians and nurses define their professional responsibilities in many ways; how they view their obligations to their patients and families will significantly condition their attitudes towards the concept of home care for medically complex children and their comfort with and effective participation in the process. There are at least three conceptualizations of professional responsibility which should be identified here: (1), responsibility for the outcomes, both bad and good, of the patient's encounters with the medical care system--instrumental and liability responsibility; (2), responsibility for (really, responsiveness to) the patient--fiduciary responsibility, in the sense of advocacy for and protection of the patient's best interests; and (3), responsibility for the spiritual and psychological integrity of the patient--priestly or sacerdotal responsibility. Often, in attending to the instrumental and liability responsibilities as professionals (and their oversight and guild organizations) see them, the other two kinds of responsibilities are slighted. Hospital care is organized to minimize error or omission of possibly effective measures, and all the choices for

intervention or nonintervention are in the hands of the professionals. There are times in hospital care, especially for acutely-ill patients, when actions are taken in pursuit of good outcomes which are, in the short term, inimical to the patient's comfort or sense of control. Likewise, some actions taken to lessen risk of bad outcomes may also be done at the expense of the patient's short-term ease or wishes. In both of these cases, the instrumental responsibility is the dominant one, and the imperatives for effective intervention and reduction of risk override all others. The hospital environment sanctions and, indeed, encourages these values and choices in the name if its curative mission. The relatively lower importance given to the other (fiduciary, sacerdotal) concepts of responsibility in the acute care setting is rationalized by the expectation (usually correct) that one, the fiduciary, is self-evident, and that the other, the sacerdotal, will be addressed by others--family, friends, clergy, social workers--when the crisis is over.

When a patient with complex care needs is transferred to home, these familiar assumptions and behaviors of the hospital environment must be reordered. Many of the moment-to moment and day-to-day choices at home will *not* be in the hands of the physicians and nurses who have provided continuous oversight while the patient was in the hospital. Indeed, many of these decisions and choices, some of them with serious potential consequences, will be made by relatively unsophisticated individuals. While a good discharge process should anticipate most of the likely occurrences, the unexpected and unprecedented do occur, at home as in the hospital. By choosing to take the medically complex person home, the family accepts some of the responsibility for possible bad outcomes, and the physicians and nurses give some of it up. That sharing of what is,

in the hospital, the sole responsibility of the professionals and the institution, is an often difficult transition for those same professionals; it may be seen by them as an abdication of their fiduciary obligation to the patient.

While families are usually made aware of the risks they assume by taking their child or adult relative home, the change of role of the professionals is less often explicitly identified and discussed. This change can be perplexing and wrenching to those who have heretofore seen their professional responsibility in a familiar and specific way. In addition, in preparation for home care, the reformulation of shared responsibility must be discussed openly between professionals and caretakers, while such discussions of responsibility and obligation in the traditional hospital settings are usually between and among the professionals. Recognition must be given to the possible tensions that dedicated professionals may feel as they face the unfamiliar challenge of revising their views of their own roles and responsibilities, and of being required to open their attitudes, concerns and traditional reactions to scrutiny by and negotiation with patients and their nonprofessional caretakers.

It is unlikely that all physicians and nurses will choose to meet those challenges or do so easily. Thus, the professionals who participate in preparation for and support of home discharge must be chosen with understanding and anticipation of the new behaviors and attitudes required; it is likely that only a few in each institution will choose to be involved in planning and implementing home care programs. Those few can and must be formed into a team in which these issues have been thoroughly discussed and from which a uniform understanding and set of

attitudes and behaviors are presented to the caretakers of the patient for whom home care is contemplated.

A special group of professionals whose imperatives and problems are usually overlooked are the administrators of acute-care hospitals, for whom the prospect of sending a medically-complex person home creates a web of conflicting interests. While wanting to do what appears to best for the patient and family, the hospital executive must remain responsive to the needs and demands of the professional staff. If there is sharp division of the staff around the appropriateness of a particular discharge and home care effort, or about the methods of preparation for it (particularly if there are extensive costs for training of home care personnel for which there is little or no reimbursement), the hospital administrator is caught between conflicting interests, each of which has compelling arguments on its side. In addition, prudent hospital risk management requires that the discharge be carried out in a manner which will not leave the hospital liable to an accusation of a sloppy or hurried process if some undesirable events do occur after the discharge is completed.

Another dilemma for hospital administrators which often goes unspoken is the pull to keep a patient in a hospital bed to maintain census or to enhance revenue, particularly if the family's third party payor is a particularly generous one. An opposite pull may result when the patient in the hospital has a payor who reimburses significantly under the costs of that patient's care. In that circumstance, the administrator may feel pressure to send the patient home as soon as possible; the result might then be pressure to shorten the discharge process. It is clear that none of these considerations should have influence on the planning or execution of

the discharge process and follow-up or the availability of the hospital should the patient need readmission. However, it is unrealistic to imagine that such pressures do not exist or might not ultimately be transmitted to the medical professionals designing and implementing the discharge process. It is necessary that the medical professionals be aware of and understand these managerial dilemmas and pressures, and that hospital management be involved in open discussion, to avoid misunderstanding or the creation of an adversary environment.

These kinds of problems only suggest the broad range of important ethical problems which are connected to home care for medically-complex children and adults. These are discussed elsewhere in this volume; however, it is important to acknowledge that these inherent dilemmas and sometimes difficult choices in home care often have important influence on the psychological state of the caretakers, the professionals and the patients as well. When these are seen and addressed as ethical and value choices, rather than as dogma or mandated practice, a different sort of problem-solving process will ensue, with improved understanding, acceptance, comfort and mutual support among all involved.

DESIGN OF THE DISCHARGE PROCESS AND PLAN: THE ANTICIPATION AND REDUCTION OF STRESS

Some specific aspects of the plan for discharge of the medically complex person from hospital to home care should be addressed in anticipation of likely stresses and to reduce the consequent psychological problems.

Concern about adequacy of funds to support home care is universal, persistent, anxiety producing and erosive. A financial plan which does not threaten to seriously deplete the family's resources and which has certainty into the future is absolutely essential. Unfortunately, it is not easy to construct such a plan in the face of existing reimbursement policies of the Federal and State governments, and the limits to payment by private insurers and "managed care" organizations. Without reasonable assurances of adequate and continuing financial resources, nearly all families will eventually cave in to the anxieties of looming bankruptcy and the inabilioty to provide for both the family's basic needs and the essential care for the affected person. Thus, a sound financial plan, no matter how difficult to achieve, is an absolute prerequisite for discharge to home.

Other important considerations which will help to minimize stress include: a plan for screening and supervising paid and volunteer caregivers; careful consideration of the best use of space in the home for the efficiency and safety of the patient's care and for the privacy of the patient and of the rest of the family; planned periodic respite for the primary caregivers; assurance of availability of those supplies and equipment (and repairs and replacements) essential to care; pre-arranged and well-informed appropriate emergency services; educational and recreational plans for the patient; specific attention to the needs of others in the household; the easy availability of professional counselling for the family, other caregivers and, where appropriate, for the patient as well.

The process of planning for discharge can also be designed to address and possibly reduce the most common anxieties and fears of the

future caretakers of the child or adult in the home setting. It is clear that, above all, the caretakers must be active, intensive and informed participants in every step of the planning process. That process should include, in addition to technical training of the caretakers, extensive discussions about the roles of family, volunteers and paid professionals in the ongoing care program. Perhaps most important for long-term success is the establishment of a climate in which the family feels confident that they can renegotiate and discuss their initial commitments and decisions without feeling guilt about having failed or appearing incompetent.

Changing family circumstances may require reevaluation and rearrangement; such events as the illness or exhaustion of one of the primary caretakers, the birth of a new child, or changes in the needs of the patient or siblings as they pass through developmental stages may temporarily or permanently render even the best-conceived discharge and care plan inappropriate. It is best that such needs for renegotiation be recognized before discharge, in order that they may be responded to rapidly, before the entire home care program crashes or the patient is endangered. Finally, it is of fundamental importance that the boundaries of possibility for recovery and development be clearly outlined by the professionals and that the family is helped to have neither unrealistic expectations nor undue pessimism; both can seriously impede effectively meeting the patient's needs.

CONCERNS ABOUT THE FUTURE: Home care for medically complex children and adults is a relatively new venture; there are few data available about outcomes. While we can guess at some of the anxieties and uncertainties for these patients and their families, it is likely that others, not now anticipated, will emerge as more people with a wider

variety of conditions are moved from hospitals to home. They and their families will be the sources of yet unplanned articles and chapters. New issues will emerge, such as care for medically-complex children as their parents age, and the nature of the childrens' lives as adults. These will replace the present concerns about caretaker performance and the success of the original care plan. We can be sure that financial issues will be a constant focus for the families; concerns about present funding will merge into uncertainty about long-term funding unless and until new forms of governmental or private insurance payment are elaborated which acknowledge the essentially permanent dependence of these individuals and their families on outside financial support. All of these problems can and will have important psychological consequences; the best we can offer to these families is our unflagging availability for discussion, consultation and advocacy and our sincere willingness to walk this unfamiliar path with them as their lives unfold.

The movement of people with complex medical problems from acute-care hospitals into home settings is certainly going to increase, impelled by social forces which are still not entirely clear. This significant shift in medical practice and in the expectations of families will certainly continue to generate stress, conflict and tensions in the families, the patients and the professionals who work with them. Changing social structures and public policies will add to the uncertainties for all parties, and ethical dilemmas will continue to arise as we collectively confront our values and choices in a rapidly changing landscape. This prospect of uncertainty carries with it also the prospect of significant psychological stress for all concerned and a requirement for continuous responsiveness to the changing needs of those who are at the focus of this complex

enterprise. The responsible professionals will be best prepared to meet those needs if they are clearly aware of their own values and conflicts, if they understand the difficulties which the patients and families face and honor their concerns and choices, and if they recognize that each decision along the way must be revisited and, if necessary, reshaped as the patients' and families' interests and needs evolve.

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